



Huntington's Disease Society of America

Information to include in a support letter to Social Security

Provide specific examples (including dates) of how HD has impacted the person's life from the time of symptom onset to the present. Examples of possible topics that you could include in the letter are as follows:

1. HD person's ability to perform daily tasks and follow basic instructions.
 - a. Does (s)he remember to take their medication?
 - b. Does (s)he have any responsibility around the house (or need reminders to do things)?
 - c. Does (s)he leave the house/require supervision?
2. HD person's ability to perform personal care tasks for themselves (cooking, bathing, and dressing).
3. Changes in mood, behavior, or physical condition.
4. What was (s)he able to do before their disease that they cannot do now?
 - Consider things like house/yard work, hobbies, driving, shopping, and social activities

A sample letter is attached to give you an idea of what to put in the letter. **You should address your letter to the Social Security Administration and date and sign it.**

Sample Friend Letter

6-5-17

Dear Social Security Administration,

I met [REDACTED] when we were thirteen years old and have been best friends and brothers since that first day. We are huge nerds and martial artists. Growing up [REDACTED] has always had a mind that was a steel trap and he could remember the most remote details of which ever book series that we were reading. He is a true warrior at heart and takes his martial arts very seriously. He trained and honed his body to be like the masters of the old days.

When we found out that he has Huntington's on Feb. of 2012 things started to take a turn for the worst.

MEMORY

As I said before [REDACTED] had a mind that was a steel trap and as sharp as a sword when we were younger. Now he has to call me and ask me questions about books and movies that he just read or watched. One of the more scary incidents that I have seen is when we went and saw the movie Thor: Dark World when it came out in the theaters. This movie hit theaters on November 8th of 2013. We had taken our children to see the movie on a Saturday. [REDACTED] called me the following Sunday to tell me about the movie and how awesome it was. I had to remind him that I was there with him and that I sat next to him for the movie.

For the martial arts [REDACTED] taught he had to know forms that are called kata like the back of his hand. Brandon knows upwards of fifty different kata. These kata are a series of movements to build muscle memory for all the different techniques you would learn. He used to be able to run them backwards. He now has to watch videos online just to remember even the most basic kata.

Around April of 2015 [REDACTED] got a job working with me for a utility tree trimming company. He had the hardest time just to remember the most basic tasks of each day. Each morning when the truck would get to the job site it was always the same routine of wheel chocks, cone off the truck, and to put out work signs. [REDACTED] would always have to be reminded what to do and what to set out. He also would forget where things were on the truck even though everything that is on the truck has a predetermined place.

Muscle Failure

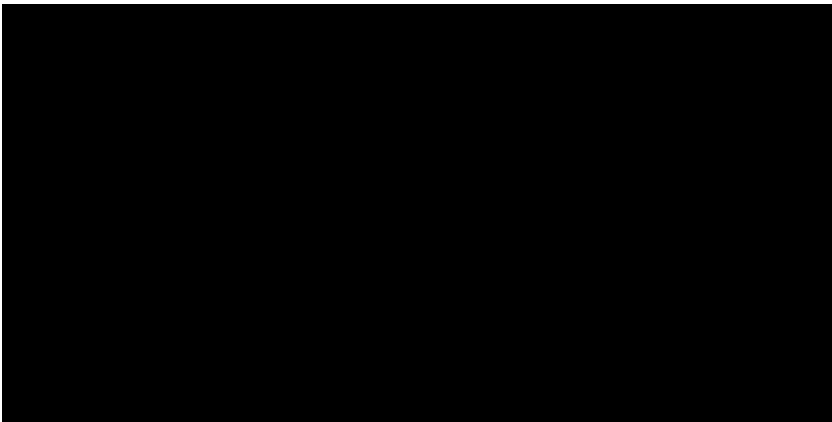
[REDACTED] has always been a very fit and active man. He would normally spend six days a week working out whether it was weight lifting or martial arts training. He always took great pride in how strong he was for some one of his size. In the last year there has been a very noticeable decline in the way that his muscles are working. I have seen him when he was lifting weights slowly have to use lighter and lighter weights. It seems as if his body is working independently of his mind. Like there are two people in his body trying to run the show. I have also seen the same thing when we are practicing martial arts together. He would want to throw a technique but instead of what he wanted to do it would be a

different technique. This also happened when he was working with me. I would watch as he was climbing a tree to trim it and I could see what he was attempting to do but his body just wouldn't let him. He would have to stand there and really focus just to get the correct movement to finish his task.

Mood

Growing up [REDACTED] was always happy and joking around. In the last three years that has changed drastically. He has a broad range of mood swings. Things that are small and insignificant will now send him into a blind rage. He will randomly just get sad and melancholy which will then be followed with regret and anger just because of the way he was feeling. We were at the gym on 6-1-17 and a younger kid asked him a question and [REDACTED] just got very angry and snapped at the kid for bothering him. Brandon after a little while went over and apologized for his actions. [REDACTED] cannot control these actions and when an episode happens he will get so down on himself that he will just stay at his apartment for a few days to try and calm himself down over it.

In conclusion, I've watched a man that was proud, giving, and loving turn into someone that cannot control his body or mind. Please reconsider [REDACTED] for getting aid and the help that he needs. Please help my brother.



Sample Parent Letter

December 30, [REDACTED]

To Whom It May Concern,

We are the parents of [REDACTED]

Before Adult Onset Huntington's Disease symptoms appeared in [REDACTED], she was focused and goal oriented, achieved her Master's Degree in Speech Language Pathology, and was a dedicated Speech Language Pathologist in clinical and school settings. [REDACTED] was vibrant and outgoing and made friends easily. She went on mission work trips to Mexico, Peru, and Africa, and enjoyed trying new things like painting, guitar, dancing. She was athletic, competing in ski racing, soccer, and mini-triathlons. She enjoyed recreational activities; mountain biking, water skiing, and hiking.

We began to notice changes in [REDACTED] behavior in the latter months of 2016. She was withdrawn, sad, and disconnected. We also noticed that she was clumsy, uncoordinated, and had fallen down our stairs a couple of times while visiting during the Christmas holiday.

While driving down to visit [REDACTED] and her family in June of 2017, [REDACTED] told us on the phone that she had quit her job with the [REDACTED] County School District, which concerned us greatly, believing that this was a move that was totally out of character and irrational; she was the primary financial support for the family, and without her income they would not be able to make ends meet. Visiting with [REDACTED] and her family on that trip, we found her more withdrawn than over the holidays, and our concerns grew. It was at this time that we reached out to a genetic counselor, and then a social worker with Huntington's Disease Society of America. [REDACTED] birth father had been diagnosed with Huntington's Disease and committed suicide, and we were concerned that [REDACTED] was exhibiting signs that could be consistent with that disease. These conversations led to [REDACTED] being examined first in [REDACTED], and eventually diagnosed with Adult Onset Huntington's Disease at [REDACTED] University in [REDACTED].

Since [REDACTED]'s diagnosis, we spent more time traveling to visit and help take care of [REDACTED] and her family. I [REDACTED] have had to quit my job in order to help care for [REDACTED] and her children. Family financial support has allowed them to pay their bills, but we realize that this support cannot be sustained. [REDACTED] is unable to take care of her 3 children while her husband, [REDACTED], is working. Before moving to [REDACTED], the 2 older children would have to go to daycare so [REDACTED] could focus on the youngest child.

[REDACTED] continues to decline; physically, mentally, and emotionally.

- ✧ Her slurring of speech has increased and is constant
- ✧ [REDACTED]'s ability to process incoming information is slow. When speaking with her you have to pause and wait for her to think about what you said, wait for her to gather her thoughts, and then she responds slowly and with slurred speech
- ✧ She frequently has choking episodes while eating
- ✧ Her coordination has noticeably declined, she has fallen on stairs and on flat ground when out for a walk, she's unable to perform movements like jogging or jumping jacks

- ✧ She exhibits increased chorea, and involuntary movements are constant
- ✧ With [REDACTED]'s unsteady gait, uncontrolled movements, and her slurred speech, she has a drunken appearance
- ✧ She is unable to maintain focus and exhibits poor decision making
- ✧ [REDACTED] has lost strength, and has trouble grasping and holding onto items
- ✧ Her dexterity has declined; she has difficulty with tasks such as cutting paper, cutting vegetables, her handwriting is barely legible
- ✧ [REDACTED] has difficulty planning and preparing meals.
- ✧ She has difficulty driving, and has had 5 minor accidents in the past few years
- ✧ Emotionally, [REDACTED] cannot deviate from plans without becoming upset
- ✧ She is sad, withdrawn, and disconnected.
- ✧ [REDACTED] has facial twitches and a glazed or distant look in her eyes.

Because of what we see as [REDACTED]'s current condition, her extended family has helped them move to [REDACTED], where we can be regularly involved and care for her and her family. We are also aware that Huntington's Disease is a progressive disease, and she will continue to decline in all the areas that she has already exhibited difficulties. We do not believe that she is capable of any kind of work, and have worked hard to bring her and her family to [REDACTED], as we also do not believe that she is capable of caring for her family without additional assistance.

[REDACTED]'s Adult Onset Huntington's Disease diagnosis has devastated her immediate and extended family. As her parents we are saddened that [REDACTED] can no longer perform her job as a speech language pathologist and don't believe that she is not capable of keeping up with the demands of any type of job. We are also saddened that [REDACTED] cannot be the mom that she so desperately wanted to be. She has trouble preparing their meals, bathing the children, reading stories to them, setting and following routines, and recognizing her children's emotions. [REDACTED]'s diagnosis rules our daily life. It is constantly on our mind and part of our daily routine by helping care for the kids, preparing meals, shopping, house work, getting [REDACTED] to her appointments, providing [REDACTED] and her family with a place to live, providing guidance on finances, child rearing, planning for the future, and how to care for [REDACTED] and her family.

Sincerely,

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

Sample Spouse Letter

Date

Dear Social Security Administration,

I believe that XXXX and I met at a biker club reunion when we were kids.

In **1995**, we got married.

We took a vacation in the spring of **2000** with my parents and sister in the Dominican Republic at an all-inclusive resort. She was miserable the whole week, never smiled, never wanted to do anything and complained about everything. My mother sat with XXXX by the pool and tried to talk with her. XXXX burst out crying for no reason. I did not know what to do. I asked XXXX why she was like this. All she said was she did not feel comfortable and wanted to go home. This is not a normal reaction to a vacation. When we got home XXXX was still not herself.

In **2004**, I was lucky and got a job in West Virginia but rented a house in Virginia. XXXX was not happy about the move and said the rental house was too small. We had regular arguments about the house, the area and the lack of friends. XXXX continued to hoard. She had a better excuse now – We can't throw anything out, it's all in boxes and we can't go through them now because we don't have the space to open things up. XXXX was getting harder to talk to and it was becoming more difficult to reason with her.

During the year **2005** XXXX was acting opposite of her nature. She would be sad, distracted, apathetic, forgetful, and unable to follow directions. In **2005**, I got a call at work that there had been a fire at my house. I rushed home and found the kids across the street, no fire trucks in front of the house but XXXX was standing outside the house crying. I asked what happened and she said she left plastic bowls in the oven and turned it on and forgot about it until the smoke started pouring out of the oven and set off the smoke detectors when she was upstairs with the kids. She got the kids out of the house and across the street to her friend's house to call the fire department. They arrived and found the source of the smoke.

In **2006**, we invited a work friend and his wife over for dinner. I bought frozen beef stew or stroganoff for dinner. XXXX's only job was to stir the pot and keep the meal from sticking and burning. About an hour before dinner we started smelling a strange smell and started to investigate. We ended up in the kitchen and there was smoke coming out of the pot on the stove. XXXX thought she turned the heat down but did not and she did not stir the pot. There was burned food on the bottom of the pot and smoke pouring out. I took the burned pot of food threw it into the back yard. We were never able to sand out all the burn. This was a simple job that XXXX once could have done. She lost her sense of time and forgot something simple.

In **2007**, she fell down the stairs two different times but did not hurt herself enough to need a hospital. XXXX continued to hoard and house cleaning was almost non-existent except for when I did it. XXXX just did the dishes poorly. Life went on but XXXX did not seem like she was very much aware of the events around her. Her world seemed to shrink. I talked to XXXX about starting up her hobbies so she would have something to do and somewhere to go and someone to talk with. She said there was no sense in that because she no longer cared about them. She had lots of temper tantrums and some screaming as her ability to speak convincingly decreased.

In **2010** we found out from her Uncle that her Mother tested positive for HD. XXXX started going to a psychologist before we found out about her Mother's test results. XXXX liked to go to the psychologist to talk. I gave XXXX instruction lists of things to do to keep her busy at home. Her apathy took over and she did very little and started sleeping a lot during the day. She also started making humming noises and humph sounds when I was around.

XXXX and I went to Dr. XXXX for an evaluation in February **2013**. I was amazed at how poorly XXXX did in the testing. I had no idea how bad she really was until I watched her try to follow directions from the Doctor. This is when I first actually fully realized how bad XXXX really was and how much damage the HD had caused. The Doctor found her to be completely disabled and unable to function in normal work environments. We started out with the same dose of XXXX and added XXXXX for her depression. She feels a little less negative, has a little less apathy and is no longer talking about divorce. We have requested Dr. XXXX to double the amount of XXXXX to improve her control.

I hope this letter has shown how XXXX went from being an outgoing, active, intelligent, capable hard working and fun loving lady to a reduced function introvert that sleeps most of the time (continuous muscle contractions are tiring) and seldom ventures far from home.

Please help us by using this and other non-medical evidence to award XXXX the SSA disability status she deserves, due to her 20 to 25 year downhill slide caused by her genetically-inherited Huntington's disease.

Thank you,

{INK SIGNATURE}

XXXX XXXXX – XXXX's Husband

November 11, 2013

Sample Employer Letter

March 20, 2018

RE:

██████████
██████████
██████████

Employment Dates: 6/25/2012-07/28/2017

To Whom It May Concern:

██████████ was hired as a Staff Accountant at the Company's headquarters location in Hoffman Estates, Illinois on Monday, June 25, 2012.

At the time of hire, ██████████ diagnosis had begun to limit his daily activities and he was unable to work full-time hours on a sustained basis. It was for this reason that the CEO of our ██████████ ██████████ made a decision to hire ██████████. The intent of hiring ██████████ was to allow him to continue to be employed as his condition progressed in a protective environment that could accommodate the flexibility he may need.

During the initial employment period beginning June 25, 2012 through approximately June 2015, ██████████ was able to perform assigned basic accounting duties satisfactorily although not always on a full-time schedule. During the first half of the year of 2015 ██████████ began to demonstrate a pattern of frequently being off task, difficulty concentrating, and became error prone. For this reason, it became necessary to limit the work assigned to ██████████ and to assign a team member to check the work he performed for accuracy.

In July of 2015, a determination was made that ██████████ could not perform basic accounting entries (calculate an entry on his own) without error. A decision was made to limit the work assigned to ██████████ to include only those tasks involving fixed assets. All of the other work ██████████ previously performed was assigned to other team members.

The fixed asset tasks assigned to ██████████ involved tracking the inventory and depreciation of fixed assets. This is considered an entry level task, which an inexperienced accounting clerk can typically perform without error. Further to this, the assigned fixed asset tasks assigned to ██████████ would typically take an entry level accounting clerk approximately twenty hours per week to complete.

The fixed asset tasks began to take ██████████ approximately forty hours per week to perform. ██████████ began to demonstrate difficulty concentrating and was frequently off task. Additionally, ██████████ continued to make errors.

The efforts to limit the assigned tasks of [REDACTED] did not improve his work performance or accuracy. For this reason, beginning in July of 2015, all of [REDACTED] work product was verified for accuracy by an Accounting Manager. If errors were identified, they were corrected by the Accounting Manager before the entry was finalized.

[REDACTED] symptoms began to consistently interfere with his work performance and attendance. [REDACTED] it was agreed that the accounting team would continue to accommodate [REDACTED] by allowing him to continue to work in a limited capacity with direct oversight of his work.

In February of 2016, a determination was made that [REDACTED] could not perform the tasks assigned involving fixed assets. Methods were put in place that required [REDACTED] to only submit an entry, rather than evaluate and or calculate it himself. However, upon audit of his work, it was found that [REDACTED] consistently failed to perform the task(s). Specifically, he did not submit the entry when required or pursuant to the schedule of tasks. Additionally, [REDACTED] became non responsive. An effort was made to limit the amount of emails received by [REDACTED]. As a result of these efforts, [REDACTED] received less than ten emails per day. In some cases the email was a request for a fixed asset number. [REDACTED] consistently did not respond to these requests. [REDACTED] demonstrated a continued decline in ability to process basic requests to look up a number or return an email.

As a direct result, all duties outside of recurring entries related to the close of the Month were removed from [REDACTED]. He was assigned tasks that involved him simply 'pushing a button' by submitting an entry made by a co-worker on his behalf. An example of this was an amortization performed by another accountant, but assigned to [REDACTED] to submit. These minimal tasks involved approximately eight hours of work per month. Oversight continued. There continued to be a demonstrated pattern of [REDACTED] failing to submit the assigned entry.

At this crossroad, the symptoms of [REDACTED] diagnosis were evident in the workplace. He was spatially disoriented. This included becoming confused about tasks previously well-known to him during the years he has been an accountant and since his employment begun with our Company. He demonstrated memory impairment and would forget an instruction or to return a call or to answer when asked. There were changes to [REDACTED] personality. He was not even tempered. He had low-frustration levels. He was withdrawn from others. Perhaps because of his apparent physical and cognitive deterioration. He seemed discouraged and embarrassed to come outside his office. At times, he would randomly walk throughout the office and yell out by way of verbalizing but without words.

Additional accommodations were made including having a co-worker check all of [REDACTED] work, verifying every entry [REDACTED] was assigned to submit, and actual oversight of his well-being while [REDACTED] was in the office. Both [REDACTED] performance and attendance were not addressed with [REDACTED]. It was understood that the Company would continue to accommodate [REDACTED] decline in function until such time as [REDACTED] determined he could no longer perform any work.

In March of 2017, [REDACTED] demonstrated increased symptoms and was commonly confused or overwhelmed with the task of submitting an entry.

██████ developed distinct symptoms of constant tongue/mouth movements, rhythmic twitching of fingers and hands, and a pronounced listing and twitching as he walked.

At his point, ██████ could not submit an entry without someone virtually checking and correcting his work at all times. The task assigned to ██████ of submitting an entry made by another co-worker was reduced to a total of five journal entries at month end. This task involved approximately two hours of work per month. The balance of ██████ time was spent in his office, provided to him for privacy. ██████ routinely used the internet, took a nap, coordinated and attended medical appointments, and otherwise used working hours for personal tasks.

Further to this, ██████ had developed an all-consuming obsession about food and the bathroom. Specifically, he was observed spending an entire day arranging snack food items on the surface of his desk, and would be routinely observed going to and from the bathroom carrying a shopping bag filled with his own personal supply of napkins, toilet paper, and paper towels.

In July of 2017, it was determined that ██████ was unable to perform any work tasks and that his disturbance in mood could not be accommodated in the office. His symptoms interfered with his ability to function. Staff members had been more than willing to pitch in to facilitate the accommodations that had been made for ██████ thus far. However, over time, it became impossible for us to keep providing this amount of support, and sadly, a decision had to be made to end his employment.

Sincerely,

██████████
Vice President, Human Resources